SEXUALITY AND DEMENTIA: FOR BETTER OR WORSE?

Elizabeth Lightbody, ST6 Old Age Psychiatry, Gartnavel Royal Hospital, Glasgow.
Elizabeth.Lightbody2@ggc.scot.nhs.uk

Introduction
The population is ageing and at the same time our culture is becoming increasingly open about sex and sexuality. However, older people’s sexuality remains something of a taboo and this is no truer than when considering sexuality in the context of dementia.

Sexual disinhibition is recognised as one of the behavioural and psychiatric symptoms of dementia (BPSD) and is a common reason for referral to old age psychiatric services. These referrals often come from care homes and sexual disinhibition can be a reason for seeking alternative placement for a resident. Sexual disinhibition is reported in 7% of Alzheimer’s disease sufferers (Burns et al, 1990) but may be more frequent in other types of dementia such as frontotemporal dementia. Sexual problems associated with dementia include inappropriate sexual acts in public, inappropriate sexual talk, false sexual allegations and sexual abuse (Haddad and Benbow, 1993, part 1). Increased or decreased libido can both cause problems, and the change of role and identity when one partner develops dementia can impact on established relationships. Sexual problems in dementia have a range of possible causes including neuronal loss in the frontal and temporal lobes, mood disturbance, psychosis, misidentification and misinterpretation of social cues due to cognitive impairment (Haddad and Benbow, 1993, part 2).

We all, however, have a right to sexuality and many people with dementia continue to enjoy satisfying sexual relationships. Sexuality enhances our wellbeing, regardless of age or illness. Sexuality, which includes romance, companionship, touch and affection, is an important predictor of quality of life (Rheaume and Mitty, 2008). The World Health Organisation defines sexuality as “a central aspect of being human throughout life” and “encompassing sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.” (World Health Organisation, 2006)

In trying to balance the rights of individuals to a sexual life with the difficulties that exist because of the nature of dementia, a number of complex and sensitive issues arise. These include clinical decisions such as capacity to consent to sex, ethical dilemmas such as considering the impact of one person’s sexuality on another person and even criminal issues such as sexual abuse. These issues often become particularly apparent when someone leaves their own home and is admitted to hospital or institutional care. Here I will discuss some of the complexities which we face in this area as clinicians, and consider how we can improve our practice in order to enhance care and quality of life for our patients.
Case Study 1

Mrs L is a 60 year old woman with frontotemporal dementia. She is an inpatient in a functional old age psychiatry ward awaiting placement in a nursing home. She is sexually disinhibited, frequently touching the breasts and bottoms of staff members and fellow patients. She uses sexual language and has propositioned patients for sex. Her husband is well and continues to live at home. Mr and Mrs L had been living apart for two years prior to her admission. Mr L takes his wife home on pass most weekends. Staff believe, because of attending to her personal care, that they have sex when Mrs L is at home but they do not feel that she has the capacity to consent to this. Because of the effects of her illness, staff worry that her current wishes about sex might not reflect her previous values. Mr L tends to avoid staff when he visits and denies having sex with his wife when directly questioned. This had made the staff more concerned that sexual abuse may be taking place. However, Mrs L appears to enjoy her time with her husband and does not show any signs of increased agitation after the visits. There has never been any evidence of physical injury.

Capacity to Consent

The primary concern that staff had about Mrs L (case study 1) was her inability to consent to sex. Staff worried that if they allowed the presumed sexual activity to continue despite Mrs L’s incapacity, that they would be allowing rape. We discussed this and researched the legal standpoint and the difference between assent and consent. Although not specific to dementia, useful information was found in the Mental Welfare Commission’s publication *Consenting Adults?* (2011), which gives guidance regarding sexual relationships involving people with mental disorder.

Incapacity legislation provides a description of the constituent parts of capacity: acting, making decisions, communicating decisions, understanding decisions and retaining memory of decisions. This definition can be applied to capacity to consent to sexual relations. The Sexual Offences (Scotland) Act 2009 defines someone as incapable of consenting to a sexual relationship if they are incapable of understanding what a sexual act is, incapable of deciding whether to take part in the act or incapable of communicating their decision. Case law (X City Council v. MB, NB and MAB) adds that as part of the understanding of the sexual act a person must have an understanding of the foreseeable consequences of that act (England and Wales High Court, 2006).

Much of the literature on capacity to consent to sex has focussed on people with intellectual disabilities, with little attention paid to dementia. Lichtenberg and Strzepek (1990) detail one approach to assessing capacity in care home residents with dementia (see Box 1). In this approach, the resident is interviewed by trained staff and the person’s responses are discussed at a multidisciplinary team meeting. There, a decision on capacity would be taken by the team.
I found this a very useful framework for assessing Mrs L’s capacity and it made me question our initial assessment that she apparently lacked the capacity to consent. Mrs L recognised Mr L when he visited and knew him as her husband. She was able to communicate what she wanted, although we believe this to have been heavily influenced by the symptoms of her illness. Little was known about Mrs L’s premorbid sexual behaviour and values and this was unfortunately something that her husband was reluctant to discuss with us. We did, however, know that the couple had been living apart prior to admission although this was said to be because she had moved in with another family member to help care for them. Because of her language impairment it was difficult to assess Mrs L’s understanding of her sexual relationship and the possible risks, or what precautions she might take against any risks.

Another useful guide on assessing adults’ capacity to consent to sex can be found in Murphy and O’Callaghan (2004) (Box 2). They developed a functional approach to defining capacity to consent to sex in people with intellectual disabilities but I believe it could also be used for people with other mental disorders.

Box 1: Assessing capacity of dementia patients to consent to sexual relationships (Lichtenberg & Strzepek, 1990)

<table>
<thead>
<tr>
<th>Assess awareness of the relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the person know who is initiating sexual contact?</td>
</tr>
<tr>
<td>Does the person believe the other person is their spouse/partner?</td>
</tr>
<tr>
<td>Can the person articulate what level of intimacy they would be comfortable with?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assess ability to avoid exploitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the behaviour consistent with former beliefs and values?</td>
</tr>
<tr>
<td>Does the person recognise the concepts of choice and voluntariness?</td>
</tr>
<tr>
<td>Does the person have all the information needed to make a decision?</td>
</tr>
<tr>
<td>Does the person have a guardian?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assess awareness of possible risks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the person realise sexual contact may be time-limited?</td>
</tr>
<tr>
<td>Can the person describe how they would respond if and when the contact ends?</td>
</tr>
<tr>
<td>Is the person aware of potential physical or emotional harm?</td>
</tr>
<tr>
<td>Can the person take precautions against risks?</td>
</tr>
</tbody>
</table>

Box 2: Capacity and Sexual Relationships (Murphy and O’Callaghan, 2004)

1. basic sexual knowledge (e.g. of body parts, sexual relations and sexual acts);
2. knowledge of the consequences of sexual relations, including sexually transmitted diseases and pregnancy;
3. an understanding of appropriate sexual behaviour and the context for this;
4. an understanding that sexual contact should always be a matter of choice;
5. the ability to recognize potentially abusive situations; and
6. the ability to show skills of assertion in social and personal situations and to thereby reject any unwanted advances at a given time.
Awareness of potential risks is part of any capacity assessment. The possibility of sexual abuse was a particular source of concern for the staff in the case of Mrs L. At first we found it difficult to specify risks other than “sexual abuse” but potential risks which we managed to identify included having sex which she would not have consented to, indignity and sexually transmitted infections. Sexually transmitted infections are on the rise among older people (Duffin, 2008) and often people in this age group have had no formal sex education and wrongly believe themselves not to be at risk (Wooten-Bielski, 1999). Although often not even considered by health professionals, sexual health advice may well be beneficial for some older people. Overall we felt that in this case there was no real evidence that Mrs L was at risk of significant harm and so we did not intervene. We continued to monitor the situation and kept trying to engage Mr L better with the team.

**Attitudes and Values**

My first reaction when I met Mrs L was embarrassment. I wanted to stop her sexually disinhibited behaviour and protect her from sex that she could not consent to. Other staff felt the same at first and many patients and relatives had complained about her behaviour and language. However, after further discussion and time spent with the patient we could see that much of what we felt related to our own attitudes rather than to Mrs L’s needs.

Our culture can be both ageist and sexist. Sex is portrayed as something for the young and beautiful and older people’s sexuality is ignored. Younger people tend to view older people as sexless and unattractive (Ehrenfeld et al, 1999) and they overestimate the presence of sexual dysfunction in older people (Allen et al, 2009). People see sex among older people as either funny, disgusting or non-existent (Kessel, 2001). However, older people do remain sexually active and sexually satisfied and they are positive about their sexuality. The Kinsey report from 1948 documented that 80% of over 60s were sexually active and there is some evidence that both the quantity of sexual activity and the quality of sexual satisfaction among older people is increasing over time (Beckman et al, 2008). Sexuality continues to contribute to quality of life in older age (Robinson and Molzahn 2007), including for those living in care (Aizenberg et al, 2002).

Sex in older age is seen as even less acceptable by the public if you include physical impairment or, worse still, cognitive impairment (Allen et al, 2009). However, we know that sexual intercourse and the expression of intimacy remain important among people with dementia. Dourado et al (2010) reported that 60% of patients with mild to moderate dementia in their study continued to engage in sexual activity, and only a minority expressed dissatisfaction. In another study, 22.5% of married people who were referred to memory clinics continued to be sexually active (Ballard et al, 1997). Those patients who continued to be sexually active tended to have higher scores on cognitive testing than those who did not.

Even those who work with and care for older people hold discriminatory attitudes. Care home staff respond differently to incidents involving male or female residents (Archibald, 1998) and families are more protective of female relatives involved in intimate relationships (Ehrenfeld et al, 1999). One survey of care home staff and other
professionals explored attitudes to sexuality and dementia in care homes. There was agreement that sexual expression is healthy and promotes quality of life, but less agreement when it comes to actually encouraging affection and intimate behaviour (Holmes et al., 1997). Healthcare professionals do not ask older patients about sex (Davies et al., 1998), and some patients report that their doctor would be more uncomfortable discussing sex than they would be (Warner et al., 2008).

Staff looking after people with dementia must be aware of their own attitudes and values as this can influence their approach to cases. Individual attitudes are important as well as the wider culture in care homes and hospitals and among the general public. In the case of Mrs L, I believe we made significant progress simply by recognising our own attitudes and the impact they were having on our judgements. We tried to consider whether sexual expression was important for Mrs L and whether it was our role as healthcare professionals to decide her intimacy needs. We asked ourselves if we were treating her differently because of her age.

We also had to overcome any embarrassment in talking about sex and discussing it with Mr and Mrs L, as well as other patients and their families. This raised yet another difficulty as there is no accepted shared language for talking about sex: what is an acceptable term for one person could be offensive for the next, and medical terms might distance some people from any discussion. This lack of a shared language is also true even among health professionals. Confidentiality must not be forgotten and a balance must be reached between the need to discuss relevant issues with the family and multidisciplinary team and the need to maintain someone’s privacy. In having these sometimes difficult discussions in relation to this case I hope that we may have gone a small way to improving understanding, because attitudes will never change if sex and dementia remains a secret taboo.

**Risk Management**

**Case Study 2**

Mr G is a 78 year old man with Parkinson’s disease and dementia. He has recently started buying pornographic magazines on a daily basis and masturbating in front of his wife. She finds this very distressing and embarrassing. Mr G leaves the magazines visible in the living room of the house where they were found by his young grandchildren. As a result his grandchildren are no longer allowed to visit him. It was felt that Mr G was suffering from the impulse control side effects of the dopaminergic medication for Parkinson’s disease. When the dose of his medication was reduced, his behaviour lessened. He continues to buy pornographic magazines but does not masturbate in front of his wife and he now keeps the magazines in a private place.

Positive risk management, or risk enablement, is based on balancing the positive benefits of taking risks against the negative effects of avoiding risk altogether. Risk enablement
uses a four step approach: understanding the person’s needs, understanding the impact of risks, enabling and managing risk, and risk planning. Using this approach helps us identify risks and their impact and assess these in terms of severity and likelihood. The risk of harm needs to be weighed against the contribution of the behaviour in question to quality of life. Where risk outweighs any potential benefit then we should intervene.

- Identifying the person’s needs – Mr G gets pleasure from his behaviour and wishes to continue it. However, he also wishes for his family to be happy and for his grandchildren to visit.
- Impact of harm – Mr G’s behaviour impacts on his wife, children and grandchildren. The behaviour happens frequently and is highly visible, albeit within his own home. There is a risk that other people are offended or embarrassed by his behaviour or that young children could be exposed to inappropriate material. There is no risk of physical harm to Mr G or any other person.
- Managing risk – If Mr G’s behaviour were to continue unchanged, then both his and his family’s quality of life would be impaired and some harm would result. However Mr G also has a right to his sexuality.
- Risk planning – Changing Mr G’s medication lessened his behaviour and reduced the risk of harm. Educating his family about the causes of his disinhibition and encouraging Mr G to maintain his privacy also helped.

*Nothing Ventured, Nothing Gained* (Department of Health, 2010) provides guidance on how to assess risk with people with dementia. It includes six areas for developing a robust system for managing risk: feeling loved, identity, occupation, inclusion, attachment, and environment. These should be rated in order of importance to the person with dementia. Sexuality has strong links with feeling loved, identity, attachment and environment.

Sometimes pressure is put on psychiatrists to prescribe medication in order to manage inappropriate sexual behaviour, but the role of medication is very limited. Drugs which have been tried include oestrogen, antipsychotics, antiandrogens and mood stabilisers. However, there is a lack of good quality research into the use of these drugs and therefore no real evidence that they are effective. A recent literature review by Tucker (2010) confirmed the lack of robust evidence for both pharmacological and non-pharmacological interventions. If medication is being considered, then we must remember the issue of capacity to consent. All drugs have potential to cause significant side effects, and this is of great concern where a drug is being used because of the effect of a behaviour on others, rather than for the benefit of the recipient himself. There are, of course, particular issues around the use of antiandrogens which is in effect chemical castration.
Ethical Dilemmas

Case Study 3

Miss J and Mrs M are residents in a nursing home and have started an intimate relationship. Miss J informed the care home when she moved in that she is a lesbian. She does not have a partner. Mrs M was married but separated from her husband over 40 years ago. Both Miss J and Mrs M have cognitive impairment due to dementia. Miss J appears to be the main instigator of the relationship, but Mrs M usually appears to enjoy her company. When Miss J is not there, Mrs M becomes more agitated. Miss J is felt to have capacity to consent to the relationship but staff question Mrs M’s capacity. They do not know her previous sexual history and do not know if she would have chosen such a relationship. Miss J and Mrs M kiss and hold hands when sitting together in the day room. Visitors have commented that they find this offensive.

The above case illustrates some of the ethical dilemmas which can arise in situations involving sexuality and dementia. The main ethical dilemma which arose in this case was that of respecting Miss J’s and Mrs M’s autonomy versus protecting them from harm. Staff felt that their duty of care to protect Miss J and particularly Mrs M from harm was paramount, but recognised that this was at odds with allowing them freedom to express their sexual needs. Staff also felt torn between social and moral norms, which are influenced by ageist attitudes, and the rights of dementia patients to a sexual life.

Mahieu and Gastmans (2011) reviewed the ethics literature on this topic and recommended thinking in turn about each of the four principles of biomedical ethics - autonomy, beneficence, non-maleficence and justice. However they also suggested that the four principles are insufficient when considering patients with dementia and suggest that further ethical concepts such as care, dignity and vulnerability should be included.

- **Autonomy** – Miss J can give informed consent to the relationship but Mrs M cannot. Miss J is the main instigator: is she exerting undue influence over Mrs M? Staff should find out what they can about both Miss J’s and Mrs M’s past values. Privacy should also be considered here. Do Miss J and Mrs M have access to private space? Also confidentiality should be respected as much as possible and balanced against the clinical need to share information about their private lives.

- **Beneficence** – The relationship seems to have positive effects for both Miss J and Mrs M. Any intervention by staff should be effective, the minimum necessary and of overall benefit. Some harm, such as restricting Miss J’s freedom, would likely be caused by any intervention. Our overall aim should be to improve Miss J’s and Mrs M’s quality of life.

- **Non-maleficence** – Staff must protect residents from harm and not inflict harm. If it is felt that the harm to Mrs M from this relationship was both significant and likely, and greater than the harm of restricting her freedom and autonomy, then staff should intervene.
• Justice – Should the attitudes of visitors influence staff’s approach and is this fair?
  Any intervention that staff propose should not discriminate because of the homosexual nature of this relationship.

The Care Home Environment
All the case studies presented here illustrate difficulties relating to a person’s environment. The relationship between Miss J and Mrs M would likely never have come to the attention of health professionals had they not been living in a care home. Mr G’s behaviour posed particular difficulties because of the public nature of his sexual acts. Mrs L’s sexually disinhibited behaviour, as well as her young age, made it difficult to identify a suitable care home placement for her. Some care home managers who assessed her felt that their home simply would not manage her sexual behaviour and that it would have a negative impact on other residents. There are, however, specific measures that might be taken by care homes in order to help them deal with sexual behaviour among their residents.

Almost by necessity, care homes are institutional in nature, and isolation, sensory deprivation and cognitive impairment can lead to people seeking stimulation in other ways (Hafford-Letchfield, 2008). Care homes must provide private spaces for residents. This may include secure areas to keep treasured belongings, rooms for couples to live in and for conjugal visits or do not disturb signs. Some residents might be encouraged to go on home visits. As well as physical privacy, privacy of information must also be respected. Staff should share information which is relevant to someone’s care, but that information should not be a sensational topic of gossip. The lack of privacy in a care home can make some behaviours problematic, which if carried out in private would be acceptable. For example, someone like Mr G using pornography in their own bedroom should not pose a problem.

Many care homes use pets or toys as ways of meeting residents’ needs for warmth and affection. Elderly people still like to pay attention to their personal grooming. Personal care should be provided sensitively, and there could be more access to services such as beauty salons to increase self esteem (Hajjar and Kamel, 2003). Often older people cite lack of an available partner as a reason for cessation of sexual activity, while the social environment of care homes can provide opportunities for social interaction which would not otherwise have existed.

Those working with elderly people in care homes should receive training about sexuality in dementia including terminology, residents’ rights, capacity to consent and how to respond to sexual behaviour (Mayers and McBride, 1998; Ehrenfeld et al, 1999; Higgins et al, 2004). An important aspect of training for carers and health professionals is increasing their awareness and understanding of their own values and biases (Davies et al, 1998).
Conclusions
The cases presented here demonstrate some of the key issues surrounding sexuality and dementia and there are many ways in which we can help address them. Old age psychiatrists are experts at capacity assessments and I have presented a recognised framework which can be used in this area to assess someone’s capacity to consent to sex. We are also in a very valuable position as potential teachers, as both formal and informal carers for people with dementia could benefit from having a better understanding of sexuality in dementia. This could include how to assess and manage risk appropriately, an appreciation of the positive benefits of sexuality and help in considering systematically the ethical dilemmas which arise. However, in my opinion, the most important thing that we should do is to try to address the negative attitudes that we encounter about sex, old age and dementia. In the past, sexuality in dementia has often been seen only in terms of risks, problems and symptoms but sexuality is also a core component of a person’s well-being and quality of life. Sexuality is part of being human and we all have a right to experience it.

References


England and Wales High Court (2006) EWHC 168 (Fam), [www.bailii.org/ew/cases/EWHC/Fam/2006/168.html](http://www.bailii.org/ew/cases/EWHC/Fam/2006/168.html)


Lichtenberg PA, Strzepek DM (1990) Assessment of institutionalized dementia patients’ competencies to participate in intimate relationships. *Gerontologist* 30(1) 117-120.


